Adolescent Idiopathic Scoliosis's Connections to Psychological Health and the Child Life Profession: A Literature Review

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Senior Honors Thesis

Human Development and Family Studies

University of North Carolina at Chapel Hill

Fall 2019

Approved:

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Dedication

Dedicated to Alexa Castro-Giovanni, Dashawna Dunlap, Kaitlyn Foland, Jenna Lea, and Sam Sedita. Thank you for helping me love my crooked spine. This thesis would not exist if you all hadn't been with me through the hardest years of my life and shown me that the right type of support changes lives. I'll always have your backs.

Acknowledgements

Thank you, Dr. Diliberto, for seeing how much the topic of my thesis means to me and for believing in its necessity. You listened to my concerns, let me cry, and figured out how to make it work. Thank you, also, for bringing candy and snacks to class!

Thank you, Dr. Frederick, for helping me make this thesis the strongest it could be. You pushed through my stubbornness and self-reliance and helped me look at my topic in new ways.

Thank you, David, for helping me with technology and for bringing me food in my last week of working on this thesis before my defense so I could focus on writing, and not making meals.

Abstract

The aim of this thesis is to (a) determine the psychological effects of Adolescent Idiopathic Scoliosis (AIS) on adolescents and their families, (b) determine how psychological support can improve the outcomes and care for AIS patients, and (c) determine how Certified Child Life Specialists (CCLS) can support the treatment of AIS for adolescents and their families within the framework of Family Stress Theory. A literature review, which spanned three search engines and many terms, helped to answer the research questions. Results show AIS has a varying degree of influence on many aspects of psychological health depending on patient characteristics and treatment trajectory. There is not much literature based on CCLS intervention with patients who have AIS, but the available research suggests positive outcomes. Future researchers should recruit larger, more representative samples in studies analyzing the psychological effects of AIS on patients and their family systems. They should also look more into CCLS involvement with the AIS population. Professionals involved with the care of patients who have AIS should create treatment plans that go beyond physical care and address psychological health. This should include requesting CCLS involvement and advocating for larger CCLS programs.

Keywords: Adolescent Idiopathic Scoliosis, Child Life Specialist, Family Stress Theory, Mental Health, Psychological Health, Resilience, Socioemotional Well-being

Chapter I: Introduction

Adolescent Idiopathic Scoliosis and its Connections to Psychological Health and the Child Life Profession: A Literature Review

Adolescent Idiopathic Scoliosis (AIS), the most common form of scoliosis, is characterized by the abnormal lateral curvature of the spine. AIS is diagnosed between the ages of 10 and 18 and affects 4% of adolescents worldwide (Scoliosis Research Society, n.d. A). The ratio of female to male AIS diagnoses is estimated to be between 2:1 and 3:1 (Konieczny, 2012). The cause of AIS is unknown and there is no cure. AIS cases range from mild (10 to 24 degrees), to moderate (25 to 40 degrees), to severe (41 degrees and above) and can cause visible deformity, pain, decreased organ function, and require monitoring and treatment.

AIS is a concerning diagnosis, not only because of its physical components, but also because of its potential to negatively impact mental health (Sanders, Andras, Iantorno, Hamilton, Choi, & Skaggs, 2018). Adolescence is marked by increased vulnerability; thus, a diagnosis of a chronic disease and undergoing treatments may create or worsen adverse mental effects (Barnes, 2017). Frequent appointments may require adolescents to miss school and other activities; therefore, impacting their academic performance and removing them from important social contexts. Additionally, AIS can affect self-image alters the adolescent's typical activities, habits, and appearance (Lange, Steen, Gunderson, & Brox, 2011).

In recent years, the treatments for AIS include (a) various types of bracing (Scoliosis Research Society, n.d. B), (b) scoliosis-specific exercises such as Schroth method physical

therapy (Schroth Method Exercises for Scoliosis, n.d.), and (c) surgery. Spinal fusion is the most common form of surgery used to treat scoliosis (Scoliosis Research Society, n.d. B); however, a technique called Vertebral Body Tethering is sometimes implemented (Luhmann, & Mudiyam, n.d.).Medical professionals make decisions about treatment protocols based on factors such as the age of the patient, how physically mature the skeleton is, location of the curve(s), and magnitude of the curve(s).

The current chapter presents an overview of the physical and psychological effects of AIS. The chapter also identifies the gaps in knowledge and presents the purpose of the review, the research question, and the theoretical framework guiding the review. The chapter concludes with a list of key terms and definitions.

Current Understanding

AIS affects the physical body in many ways, both physically and psychologically. Several professionals provide treatment to patients who have AIS to help slow, halt, or reverse the spine's curvature. These professionals include orthopaedists, physical therapists, and orthotists. The training these professional go through emphasizes knowledge of the human body's physicality. Research on the role and impact that medical and allied health professionals have on the treatment of AIS often centers on the cause(s) of the disease, how successful various treatments are, and whether or not the disease can be cured (Dolan, & Weinstein, 2009; Huynh, Aubin, Rajwani, Bagnall, & Villemure, 2007).

The physical effects of AIS are well documented. Less is known about how AIS affects the psychological health of adolescents. Within this thesis, psychological health encompasses both mental and socioemotional health concerns. Ascani, Bartolozzi,

Logroscino, Marchetti, Ponte, Savini, & Silvestre conducted the first study that reported mental disturbances in individuals with scoliosis in 1986. Several other researchers have attempted to bring to light the mental impact of AIS with varying results. For example, Sanders et al. (2018) examined whether there was a higher incidence of emotional distress among patients who have AIS compared to the general population and whether the presence of distress correlated with the severity of their deformity. The study found that 29% of participants reported anxiety that fell into the categorization of "at-risk" or "clinically significant" via the Behavioral Assessment System for Children, Second Edition (BASC-2), a validated 139-item survey. In another study that examined anxiety in patients who have AIS, researchers found as much as 16.6% of participants reported high anxiety but most reported low or medium anxiety (Glowacki, Misterska, Adamczyk, Latuszewska, 2013).

In addition to anxiety, another adverse mental effect of AIS is poor or distorted body image. In a study that examined female adolescents with scoliosis whose treatment consisted of Milwaukee bracing and some who additionally had surgery, data collected from observing participants revealed those with scoliosis had lower body image scores compared to controls who did not have AIS. (Noonan, Dolan, Jacobson, & Weinstein, 1997). Contrary to the findings by Noonan et al (1997), that participants' poor body image became comparable to controls who did not have AIS some years after treatment, Misterska, Glowacki, Glowacki, and Okret (2018) found that 46.67% of participants had moderate stress and 40% of participants had severe stress related to how they perceived their bodies 23 years after completing treatment.

Both anxiety and body image are common themes within research that examines the mental impact of AIS and its treatments. Other noted impacts include: (a) social problems

(Rullander, Lundström, Lindkvist, Hägglöf, Lindh, 2016), (b) adverse eating behaviors and mood disorders (Gallant et al, 2013), and (c) depression (Duramaz, Yılmaz, Ziroğlu, Bursal Duramaz, & Kara, 2018). Some researchers acknowledge the significant impacts AIS's has on mental health but in some circumstances, posit surgical treatment options as less detrimental or more likely to result in improved mental outcomes (Duramaz et al, 2018; Zhang et al., 2011).

Theoretical framework. To conceptualize the impact of AIS and its treatments on patients and the family system, it is helpful to look through a Family Stress Theory framework. In 1949, Reuben Hill introduced the Family Stress Model. Its foundation is the ABCX model in which A is a stressor event, B is the family's resources and strengths, C is the definition or meaning the family gives to the stressor event, and X is the degree of stress or crisis produced by the intermingling of the previous factors. Expanded versions of the ABCX model, particularly the Double ABCX model, incorporate post-stressor factors to reveal how families cope and adapt (Price, Price, & McKenry, n.d).

In the context of this thesis, A is the diagnosis and treatment of AIS as well as the presence of adverse psychological effects of the disease. B, C, and X are unique to each family. Professionals involved with the care of the patient and family enter the ABCX model at B. This thesis proposes Certified Child Life Specialists (CCLS) as a means of reinforcing and producing resilience in family systems within the Family Stress Theory framework. CCLS are uniquely positioned to support the mental and socioemotional needs of patients diagnosed with AIS and their families because they have the knowledge and tools to assist individuals and groups across the lifespan within medical contexts (Bell, 2015).

In sum, the current understanding of AIS is that it affects both physical and mental health, but less is known about the latter aspect. Family Stress Theory and its ABCX models help conceptualize the psychological impacts of AIS and allow the incorporation of CCLS into a care plan that would result in resilience.

Gaps in Knowledge

In comparison to research that pertains to physical aspects of AIS, research on the mental impacts of AIS is sparse. Without in depth analysis, questions of whether the literature is robust or consistent enough to assert the need for mental and socioemotional intervention and support arise. It is also unclear whether adolescents and families facing AIS are supported, psychologically, as part of their treatment plan, either by CCLS or other mental health professionals.

It is worth noting that when researchers conduct studies on the mental and socioemotional impacts of scoliosis, examination of impacts is typically limited to the patient (D'Agata, Rigo, Pérez-Testor, Puigví, & Castellano-Tejedor, 2014; Menget al., 2017; Misterska et al, 2019). This is concerning as the diagnosis and treatment of a chronic illness has impacts on those close to the patient, especially when the individual diagnosed is not wholly independent, such as an adolescent. Generally, adolescence is a time of increasing autonomy (Barnes, 2017). In this developmental period, they develop and change their identity and differentiate themselves from their family unit (Barnes, 2017). Adolescents who have chronic illnesses, such as AIS, may feel tension between their desire to become independent and to feel protected by their family in the midst of unfamiliar medical experiences (Barnes, 2017). Parents and guardians, too, may struggle with conflicting

feelings of wanting to protect their adolescent and the desire to grant their adolescent increased independence (Barnes, 2017).

Given the research and limitations explored above, this thesis proposed the inclusion of CCLS on treatment teams as a solution to the mental and socioemotional impacts experienced by those dealing with AIS. CCLS are trained to provide interventions within the health care setting to all youth (infants, children, and adolescents) as well as their adult parents and guardians. Incorporating various members attempts to foster a mutually supportive family unit so that effective coping is undertaken by the individual and sustained and encouraged by the whole system.

The Purpose

Using a Family Stress Theory, the purpose of this thesis was to examine how the diagnosis and treatment of AIS contribute to the mental and socioemotional concerns of patients diagnosed with AIS and their family members. The thesis also examined the potential benefit of having CCLS on the treatment team for AIS patient and family care and assessed the adequacy of CCLS in mitigating mental and socioemotional concerns.

Method

A comprehensive literature review utilizing three search engines and multiple search terms (which will be discussed more extensively below) was conducted to answer the research questions. First, this thesis employs a Family Stress and resilience perspective by applying principles of the Double ABCX model as a basis for understanding the stressors associated with AIS and how CCLS can be involved in building resiliency and managing the stressors associated with AIS. Second, the review presents the research to date about the

mental and socioemotional stressors of AIS on both the patient and their family system. Third, the search shifts to the Child Life profession: (a) its history, (b) its goals, and (c) its role in the treatment of patients and their families. Finally, the review focuses on any literature available that connects AIS and Child Life interventions and a model for employing CCLS on the treatment team for AIS. A presentation of literature review results and discussion of implications of the findings follow in chapters four and five.

Research Questions and Study Aims

The treatment of AIS tends to focus on the physical aspects of care and rehabilitation. There is some evidence in the literature that providing emotional and psychological support to adolescents who have AIS can have a positive impact on managing the illness. In light of the limited research on the psychological impact of AIS, the study aims to examine the literature to understand the emotional and psychological impact AIS has on adolescents. A secondary aim is to examine how AIS treatment plans can use CCLS in intervention and support for AIS. The three research questions below guided the review.

A.) What are the psychological effects of AIS on adolescents and their families?

B.) How can Certified Child Life Specialists support the treatment of AIS for adolescents and their families?

C.) How does psychological support currently available improve the outcomes and care for AIS patients?

Definition of Key Terms

Adolescent Idiopathic Scoliosis (AIS): The abnormal sideways curvature and twisting of the spine diagnosed in people age 10 through 18 years no known cause. Must have a Cobb angle greater than 10 degrees (Scoliosis Research Society, n.d. A).

Body Image: The mental picture people form of their own body. It encompasses physical characteristics, functional aspects, and psychological and behavioral attitudes (N., 2013 A).

Bracing: A non-invasive device, usually made of plastic that is worn on the abdomen to slow and halt the progression of scoliosis (Scoliosis Research Society, n.d. A). The chart below names and describes some types of scoliosis braces. Not all of them are mentioned, by name, in this thesis.

Types of Scoliosis Braces	
Name	Description
Boston Brace	Most commonly described full-time brace, usually is made from a mold and then personalized to a patient with proper cutouts and padding. This brace's straps are in the back (McAfee, 2016)
Wilmington Brace	Another type of full-time brace, but is completely custom and made from a cast of the patient's torso. It does not have any cutouts (McAfee, 2016)
Milwaukee Brace	This brace was created in the 1940s and is large and bulky. It is rarely used, today, except in some cases of high thoracic and cervical curves (McAfee, 2016)
(Rigo) Cheneau Brace	This brace is a newer type of custom brace made from measurements taken

	from the patient's body during digital scans. It is made of lightweight plastic and padding and leaves gaps or openings where corrective pressure does not need to be applied (National Scoliosis Center, n.d.)
Charleston (Nighttime) Bending Brace	This brace is made from a cast of the patient's torso and is meant to be worn only when laying down (sleeping). It applies pressure to bend the patient's spine in a corrected direction (McAfee, 2016)
Providence	Another type of nighttime, only, brace. Instead of bending the body in a direction opposite the patient's curve, this brace elevates one shoulder to apply corrective forces (McAfee, 2016)

Certified Child Life Specialist: A certified professional who helps children across the span of development and their families cope with illness, injury, and treatments by means of individualized interventions (Association of Child Life Professionals, 2018).

Cobb Angle: The most common means of measuring spinal curves, determined by measurements taken from radiographs (Thuaimer & Weerakkody, n.d).

Conservative Treatment: An approach to treating disorders and pain of the back and neck that utilizes non-surgical methods. In the context of this essay, that includes bracing and therapeutic exercises (SPINE-health, n.d.).

Degrees: The manner in which the magnitude, or severity, of scoliosis curves are measured. A straight spine is measured as 0 degrees (Scoliosis Research Society, n.d. A).

Family Stress Theory: A developmental theory that explores how families adapt to stressor events (Beckett, 2000).

Orthopaedist: A professional who specializes in treating abnormalities in the bones, especially if they are out of line and require straightening (Shiel, W. C., 2018)

Orthotists: A professional who creates and fits correctional orthopaedic devices, such as scoliosis braces (American Board for Certification: Orthotics, Prosthetics, Pedorthics, n.d.).

Resilience: "The capacity to rebound from adversity strengthened and more resourceful ... an active process of endurance, self-righting, and growth in response to crisis and challenges" (Walsh, 2006, p. 4).

Self-Image: How people view themselves. It gives them a sense of their personality, their well-being, and how they are in relationship to others (N., 2013 B).

Self-Concept: The evaluation people form about themselves, which includes physical and psychological skills as well qualities that make someone who they are. It is how people feel about themselves (N., 2013 C).

Skeletal Maturity: The milestone at which the human body stops growing (i.e. taller), characterized by the closing of all growth plates (Brewer, 2012).

Spinal Fusion: An invasive treatment that halts the progression of scoliosis by pushing the spine closer to the centerline of the body, binding it with metal implants (rods, hooks screws), and stimulating bone growth to fuse vertebra (Scoliosis Research Society, n.d. A).

Stressor: Any event that causes a variable amount of change within a family system (Price, Price, & McKenry , n.d.).

Vertebral Body Tethering: A “fusionless” surgical technique for gradual correction scoliosis in patients who have not reached skeletal maturity. The technique relies on tension from a surgically implanted tether attached along the spine and vertical growth of the spine (Luhmann, & Mudiyam, n.d.).

Chapter II: Introductory Literature Review

Scoliosis

Scoliosis is the abnormal lateral curvature of the spine, greater than 10 degrees. A spine can have one curve, typically called a C curve, or multiple curves, typically called an S curve. Doctors diagnose scoliosis via physical examination of the back and x-rays. Scoliosis can make the hips, shoulders, and ribs appear uneven. Vertebrae, themselves, can also twist, making one shoulder blade protrude (Scoliosis Research Society, n.d. C).

Aside from physical bodily differences, scoliosis may also cause pain and decrease organ function. Depending on the severity, location, and other factors of the curve or curves, individuals with scoliosis may have to undergo treatment to slow, halt, and sometimes reverse the curvature (Scoliosis Research Society, n.d. C). Treatments for scoliosis include specific types of physical therapy, various types of braces, which the patient wears around their trunk, and surgery (Scoliosis Research Society, n.d. C). Patients may have to wear their brace up to 23 hours a day for months to years (Scoliosis Research Society, n.d. B). Spinal fusion surgery is an invasive procedure that takes many hours to complete (Scoliosis Research Society, n.d. B). Recovery varies but patients can expect to stay in the hospital for less than a week, barring complications, and to return to all typical activities from six months to one year post-op (Scoliosis Research Society, n.d. B). Patients may undergo one treatment or multiple treatments at the same time, such as physical therapy coupled with bracing (Scoliosis Research Society, n.d. B). They can also transfer to other treatments if their current one is not effective, such as from bracing to surgery (Scoliosis Research Society, n.d. B). Doctors may choose to monitor a patient's curve progression by taking x-rays every four to six months before deciding to implement treatment (Scoliosis Research Society, n.d. C).

There are multiple types of scoliosis called syndromic, neuromuscular, and idiopathic scoliosis. Syndromic scoliosis results from certain genetic conditions, myopathic conditions, and connective tissue disorders. Neuromuscular scoliosis results from diseases like cerebral palsy, spinal muscle atrophy (SMA), and others, or trauma to the spinal cord. Idiopathic scoliosis is the most common form of scoliosis and has no known cause, therefore it is not preventable. Idiopathic scoliosis occurs in people of all ages, from infants to the elderly, but it is most common in adolescent females. (Scoliosis Research Society, n.d. C)

The diagnosis of AIS has the potential to be a stressor as it is rarely planned for and it disrupts how the adolescent and their family system must function. Parents or guardians must find the time and money to take their child who has AIS to and from appointments. The adolescent, themselves, must adjust their schedules and plans to make room for appointments and treatments. Siblings may experience decreased attention because their parents' or guardians' focus shifts to ensuring the health and safety of the child who has AIS. All persons involved may view the adolescent's body and life differently because adolescence is supposed to be a generally health time.

Family Stress Theory

It is for these reasons that Family Stress Theory frames this thesis. Reuben Hill first proposed Family Stress Theory in response to family separation caused by war (Price et al, n.d.). The theory describes how vulnerable to crisis a family is, and is based on the ABCX model, which results from intermingling of family factors (Moes, 1999). Hill's original ABCX model included stressors (A), existing family resources (B), the family's perception of stressors (C), and degrees of stress – low, high, or crisis (X) (Price et al., n.d.) Many researchers have since had a part in expanding this model into a Double ABCX model to

include post-crisis factors and the potential for resilience (Price et al., n.d.). In the Double ABCX model, Hill's uppercase A, B, and C are lowercase and represent the same factors, but are posited pre-crisis (Sisk, 2017). Lowercase x is the family's experience of a crisis (Sisk, 2017). To the right of the x are post-crisis factors including stress pileup (aA), new and existing resources (bB), the perception of the crisis, stress pileup, and resources (cC) (Sisk, 2017). Coping and adaptation continuums are located on the post-crisis side to show how families change over time in response to all of the aforementioned factors (Sisk, 2017).

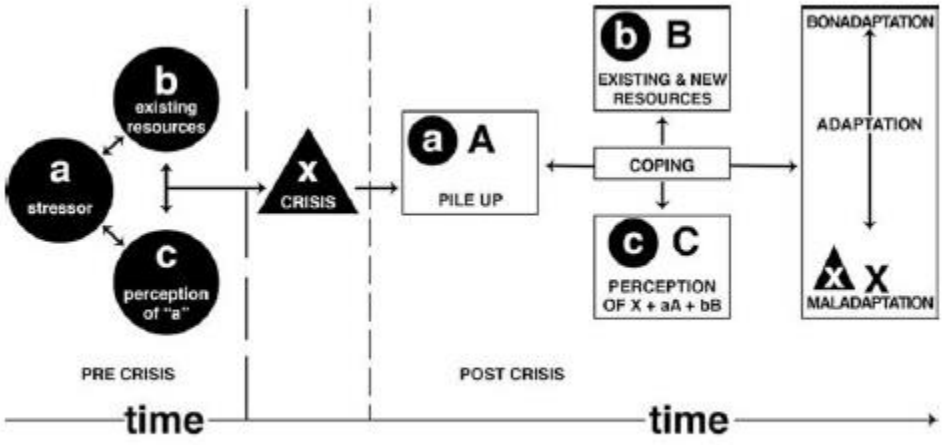

Figure 1. McCubbin, Cauble, & Patterson's Double ABC-X Model from McCubbin, Cauble, and Patterson, *Family Stress, Coping, and Social Support* (1982). Reprinted with permission and courtesy of Charles C. Thomas Publisher, Ltd., Springfield, Illinois.

Figure 1. Double ABCX Model obtained from Sisk, 2017

Family Stress Theory and ABCX models attempt to convey that the stress families experience is not inherently bad. It is a product of change(s) that are expected or unexpected and both typical or atypical. Typical stressors are those which are in-line with one's understanding of life trajectory, such as job promotions and the birth of a child, whereas atypical stressors are those which are out-of-line with one's understanding of life trajectory, such as the death of a young spouse or a diagnosis of chronic illness. Stress does not have to result from major life events. It can be a product of every-day occurrences (Price et al., n.d.).

With proper supports, families can handle stress can in a way that promotes their resilience. It is also noteworthy that Family Stress Theory places an emphasis on the family unit rather than individual outcomes.

Child Life

The Child Life Profession started with "play ladies" who sought to bring more comfort and normalcy to hospital environments, which largely ignored the developmental and psychological needs of pediatric patients. Today, the profession requires education, clinical training, and certification. CCLS still put an emphasis on play opportunities, which assist in the development of therapeutic relationships, the understanding of medical practices and procedures, and the conveyance of developmentally appropriate psychological support.

CCLS typically work in hospital settings but can also work in private practice or community-based settings. Their practice draws on many theories and frameworks, including those of Erikson's Psychosocial Development (Diaz, 2019), Bronfrenbrenner's Ecological Systems (Diaz, 2019), Family-Centered Care (Diaz, 2019), Play Theory (Diaz, 2019), and Family Stress Theory (Bell, 2015; Sisk, 2017)

History. Separation from families, discouragement from play, lack of information, and otherwise developmentally inappropriate practices characterized the pediatric hospital experience in the 19th and early 20th centuries. Originally called "play ladies", early Child Life Specialists championed the necessity of play for normative child development and anxiety relief. Some major hospitals, like Mott's Children's Hospital and Babies and Children's Hospital of New York, took note and implemented standardized play programs. Professionals like Emma Plank, "the founding mother of Child Life," and Dr. T. Berry

Brazelton were critical in asserting the need to change pediatric hospital practices and implementing developmentally appropriate support, which includes procedure preparation and explanations, play and community opportunities, and an emphasis on interdisciplinary approaches to care. In 1967, Dr. Brazelton co-founded the Association for the Care of Children in Hospitals (later named the Association for the Care of Children's Health, ACCH). In 1982, professionals from across the country founded the Child Life Council, which took over defining the profession from the ACCH. The Child Life Council developed educational and practice standards, guidelines for evidenced-based practice, and a credentialing exam for Child Life Specialist certification. Since then, Child Life programs have developed at universities and the profession has asserted its necessity in both hospital and community contexts (Beickert & Mora, 2017; Diaz, 2019; Fox, 2010).

Chapter III: Method

This chapter opens with the scope of search for the literature review, including a list of search terms, and then outlines criteria for inclusion and exclusion of search results. The chapter closes with an explanation of the analysis plan.

Scope of Search

This comprehensive literature review utilized three online search engines to find articles for analysis: (a) UNC Library Articles+, (b) Google Scholar, and (c) the United States National Library of Medicine's PubMed database with Free Full Text availability. The article search spanned three categories: (a) AIS and its impact on psychological and socioemotional health, (b) the Child Life profession, and (c) connections between AIS and CCLS. The chart below (Table 1) presents specific search terms used to examine each category.

Table 1

Literature Review Search Terms

AIS/Mental and Socioemotional Impact	Child Life Profession	Connections
Adolescent Idiopathic Scoliosis, Mental health	Child Life Specialist, History	Child Life Specialist, Scoliosis
Adolescent Idiopathic Scoliosis, Stress	Child Life Specialist, Roles	Child Life Intervention, Scoliosis
Adolescent Idiopathic Scoliosis, Psychological risk	Child Life Specialist, Resiliency	Child Life Profession, Scoliosis

Adolescent Idiopathic Scoliosis, Socioemotional well-being Scoliosis, Mental Health	Child Life, Spinal Health

Criteria for Inclusion and Exclusion

This thesis used multiple literature formats in review including (a) Case studies, (b) longitudinal studies, (c) cross-sectional studies, (d) correlational studies, and (e) others if they met further criteria for inclusion. The review excluded news articles about research findings. Only full articles available in English were included. To position the most applicable articles up front, search engines sorted results by relevance. Due to decreasing relevancy of search results, the review only considered articles up until result number 100 or page 10 of the search, depending on the search engine.

Though this thesis focuses primarily on the effects of AIS (adolescents), cases concerning infantile or juvenile idiopathic scoliosis were included if they met further parameters. The review excluded cases concerning adult-onset idiopathic scoliosis and cases concerning non-idiopathic forms of scoliosis, such as congenital and neuromuscular scoliosis, to cut down on confounding variables. The column titled "Number of Unique Applicable Resources" in tables 2-4 presents the number of sources included in the literature review that were retrieved by each search term. Sources were only counted once, even if they showed up in multiple searches.

AIS inclusion and exclusion. The reviewed included literature in which researchers analyzed AIS and/or its treatments in relation to mental health or socioemotional concerns.

The review excluded studies that presented comorbidities of AIS. The review also excluded reliability and validity analyses of questionnaires and literature that calculated Minimal Important Differences in questionnaire scores. The review excluded literature reviews, themselves, but combed them for relevant resources not found via search terms.

Table 2 shows the search results from this aspect of the literature review. The search retrieved 1,060 resources for review pertaining to research question A, 87 (8.2%) of which met inclusion criteria.

Table 2

Literature Review Results for AIS/Mental and Socioemotional Health

Database and Keywords	Total Results Returned	Number of Sources Reviewed	Number of Unique Applicable Sources
UNC Library Articles+			
AIS, Mental Health	2,061	100	12
AIS, Stress	2,573	100	13
AIS, Psychological Risk	1,221	100	6
AIS, Socioemotional well-being	14	14	1
Scoliosis, Mental Health	13,742	100	5
Google Scholar			

AIS, Mental Health	10,500	100	11
AIS, Stress	12,700	100	6
AIS, Psychological Risk	14,300	100	3
AIS, Socioemotional well-being	120	100	2
Scoliosis, Mental Health	35,400	100	1
U.S. Lib. Of Med.			
AIS, Mental Health	31	31	14
AIS, Stress	36	36	6
AIS, Psychological Risk	7	7	2
AIS, Socioemotional well-being	0	0	0
Scoliosis, Mental Health	72	72	5

Child life inclusion and exclusion. The review included literature that analyzed CCLS in relation to their roles in medical settings. The review excluded literature that discussed CCLS intervening in short-term medical missions or in community settings outside of the hospital. Since scoliosis rarely leads to death, the review excluded literature that discussed the role of CCLS in palliative care and bereavement support. The review excluded literature that discussed CCLS support in the context of parental illness. The review excluded literature that discussed the implications of dual-certified clinicians (e.g. someone certified as a CLS and a music therapist or art therapist). The references lists of articles that did not meet

full inclusion criteria but presented some relevant information were combed for applicable literature.

Table 3 shows the search results from this aspect of the literature review. The search retrieved 687 resources for review pertaining to research question B, 30 (4.37%) of which met inclusion criteria. An additional three relevant resources came from the reference lists of non-applicable resources found in the Child Life Profession section of the search.

Table 3

Literature Review Results for Child Life Profession

Database and Keywords	Total Results Returned	Number of Sources Reviewed	Number of Unique Applicable Sources
UNC Library Articles+			
Child Life Specialist, History	834,454	100	9
Child Life Specialist, Roles	642,421	100	13
Child Life Specialist, Resilience	42,633	100	2
Google Scholar			
Child Life Specialist, History	596,000	100	1
Child life Specialist, Roles	423,000	100	2
Child Life Specialist, Resilience	72,400	100	3
U.S. Lib. Of Med.			
Child Life Specialist, History	30	30	0
Child Life Specialist, Roles	52	52	0

Child Life Specialist, Resilience	5	5	0

Connections inclusion and exclusion. The review included literature that discussed CCLS in relation to intervening with idiopathic scoliosis treatment. Not all subjects included within this literature were adolescents. All interventions were in the context of spinal fusion surgery.

Table 4 shows the research results from this aspect of the literature review. The search retrieved 1,295 resources for review pertaining to research question C, five of which met inclusion criteria.

Table 4

Literature Review Results for Connections Between AIS and Child Life Specialists

Database and Keywords	Total Results Returned	Number of Sources Reviewed	Number of Unique Applicable Sources
UNC Library Articles+			
Child Life Specialist, Scoliosis	8,334	100	0
Child Life, Scoliosis	42,648	100	0
Child Life Intervention, Scoliosis	13, 495	100	0
Child Life Profession, Scoliosis	4,134	100	1
Child Life, Spinal Health	273,221	100	0
Google Scholar			
Child Life Specialist, Scoliosis	16,100	100	3
Child Life, Scoliosis	63,700	100	0

Child Life Intervention, Scoliosis	31,700	100	1
Child Life Profession, Scoliosis	18,100	100	0
Child Life, Spinal Health	793,000	100	0
U.S. Lib. Of Med.			
Child Life Specialist, Scoliosis	4	4	0
Child Life, Scoliosis	120	100	0
Child Life Intervention, Scoliosis	91	91	0
Child Life Profession, Scoliosis	0	0	0
Child Life, Spinal Health	206	100	0

Analysis Plan

Information collected for this thesis did not undergo any quantitative statistical analysis. The results section presents information by seriation of the three research questions and includes the aspects highlighted below. Family Stress Theory framed all analysis.

AIS. The review consisted of creating a chart that presented the number of applicable articles as well as creating a chart that kept track of categories of psychological and socioemotional impacts mentioned within included articles. This chart also kept track of the amount of articles which found evidence for specific psychological impacts of AIS. The results also present the number of studies that assessed impacts on parents or guardians and siblings.

Child Life. The review consisted of creating a chart that presented the number of applicable articles as well as creating a chart that kept track of identified roles of CCLS. In

the latter chart, the roles are alongside relevant experiences with AIS. This chart was made in order to make recommendations for CCLS participation in AIS care plans.

Connections. The review consisted of creating a chart that presented the number of applicable articles. The results highlight the specific instances in which CCLS were involved with AIS in the literature to show the efficacy of CCLS involvement with AIS.

Conclusion

The literature review spanned three search engines and many search terms chosen to retrieve articles pertaining to AIS and its connections to mental and socioemotional health, the Child Life Profession, and connections between AIS and CCLS. Information obtained by the literature review did not undergo statistical evaluation. Instead, the results include relevant counts and connections that help to more clearly define the psychological impacts of AIS and the roles of CCLS in AIS care plans.

Chapter IV: Results of Comprehensive Literature Review

This chapter consists of a brief overview of the Family Stress Theory, its Double ABCX model, and its relevance to the Child Life profession, as well as a review of sources collected in the systematic literature search. The first section looks at the psychological impacts of AIS diagnosis and treatment, including those on body image, depression, self-image, and others. The second section gives an overview of the Child Life profession and the roles CCLS perform, including procedure preparation and distraction, family support, and promoting resilience. The third and last section of the review presents literature in which AIS and CCLS were connected, all of which describe surgical interventions. It may be helpful to refer back to Chapter I for the definition of certain terms used in this review.

Family Stress Theory

The concept of Family Stress Theory is that stressors do not affect family members in isolation. Rather, stressors influence each family member, individually, and their reactions to stress influence family functioning as a whole. Stressors can be common, day-to-day occurrences such as those from employment and child rearing or they can be major unexpected events such as the diagnosis and treatment of chronic disease. Hill introduced Family Stress Theory and the original ABCX model in 1949 as a way to conceptualize the effect separation and reunification in wartime had on families (Price et al, n.d; Sisk, 2017).

To further illustrate the interactions of stressors with family systems, McCubbin, Cauble, and Patterson introduced the Double ABCX model in 1982. This model turns Hill's uppercase A, B, and C into pre-crisis factors. Lowercase a, b, and c represent stressors, existing resources, and the family's perception of the stressor, respectively. Lowercase x is a

crisis. To the right of the crisis are post crisis factors including stress pileup (aA), new and existing resources (bB), the perception of the crisis, stress pileup, and resources (cC). The post crisis factors show illustrate how families cope and adapt (X) to stressors over time. Adaption can be beneficial (i.e. bonadaption) or detrimental (i.e. maladaption) to family functioning. The type of adaptation a family experiences is dependent on the intermingling of all previous factors (Sisk, 2017). Figure 1 in Chapter II illustrates this model.

The Double ABCX models assists CCLS in understanding how the patients and families they work with in the hospital experience stress. CCLS are trained to assess the strengths and needs of patients and their families. Assessments should give CCLS an idea of the factors included in the ABCX model, which they then turn into interventions that attempt to promote bonadaption, or resilience. Interventions may change over time to fit the evolving needs of patients and families (Sisk, 2017).

Research Question A

A.) What are the psychological effects of AIS on adolescents and their families?

The literature below presents both evidence for and against AIS having an effect on mental and socioemotional health. Researchers used many techniques of data collection including various psychological batteries, both scoliosis specific and otherwise, and interviews.

AIS and its impact on stress. The first psychological effect of AIS discussed herein is stress. In a study that examined the changes in perception over time in female brace wearers, researchers administered the Trunk Appearance Perception Scale (TAPS), Scoliosis Research Society-22 (SRS-22), and Bad Sobberheim Stress Questionnaires (BSSQ) to 36

female adolescents. Responses from the sample revealed moderate stress in regards to having to wear a brace and low stress in regards to the presence of deformity. Results did not differ significantly at successive measures, which means stress did not get worse while wearing a brace, but it also did not improve (Misterska et al., 2013).

Leszczewska, Czaprowski, Pawłowska, Kolwicz, and Kotwicki (2012) also found evidence that conservative treatment (bracing and physical therapy) contributes to stress. In order to assess the stress experienced by patients who have AIS, the researchers administered the BSSQs for deformity and for bracing to 52 adolescents who participated in physiotherapy for their AIS and to 21 patients who wore braces in addition to their participation in physiotherapy. Results of the questionnaires indicate low deformity related stress and moderate brace related stress (Leszczewska et al., 2012).

Misterska et al. (2011) were also interested in bracing's connections to stress. Misterska et al. (2011) studied whether or not there were differences in brace related stress levels between rural and urban adolescents. To do so, they administered the polish versions of the BSSQ-brace and the BSSQ-deformity questionnaire to 30 rural adolescents who had AIS and wore a brace and 34 urban adolescents who had AIS and wore a brace. Results of the questionnaires show moderate brace related stress, low deformity related stress, and no significant difference in stress levels between rural and urban participants (Misterska et al., 2011).

The research of Zimoń, Matusik, Kapustka, Durmała, Doroniewicz, and Wnuk (2018) agrees that conservative treatments contribute to stress and that most patients experience low deformity related stress. They further asserts larger Cobb angles and age are correlated with higher stress levels. To arrive at these results, the researchers administered the BSSQ-

deformity and the BSSQ-brace to a sample of 63 patients who participated in physiotherapy to treat their AIS. A subset of 31 of these 63 patients also wore braces to treat their AIS (Zimon et al., 2018). Multiple other researchers including Weiss, Seibel, and Kleban (2014), Kinel, Kotwicki, Podloska, Bialek, and Stryla (2012), Kuru and Yilmaz (2012), Kinel, Podolska-Piechocka, Sobieska, and Kotwicki (2013; 2014; 2015) further present evidence for low deformity related stress and moderate brace related stress in braced adolescents

Misterska, Glowacki, and Harasymczuk (2011) brought surgical treatment into the discussion of AIS's impact on stress. After administering the BSSQ-brace and BSSQ-deformity to 35 adolescent females treated conservatively and 34 adolescent females who underwent surgery, they found that both groups experienced moderate treatment related stress. The conservative treatment group experienced low deformity related stress, while the surgical group experience moderate deformity related stress (Misterska et al., 2011). This difference was statistically significant (Misterska et al., 2011). Still, in line with previously discussed studies, curve severity and stress were correlated within the conservative treatment group such that higher curve magnitudes begot more stress (Misterska et al., 2011). Kotwicki, Kinel, Stryła, and Szulc (2007) had similar findings in regards to the level of deformity related stress patients who participate in conservative treatment experience, and in regards to the correlation of curve severity and treatment type influencing deformity related stress. They did not, however, find support for a correlation of age and level of stress experienced (Kotwicki et al., 2007). .

AIS and its impact on quality of life. Quality of life (QoL) includes physical, emotional, and social measures. Though some literature discussed outside of this section examined quality of life QoL or health related quality of life (HRQoL), the literature in

which the primary findings were on QoL is reported here. One such study examined the relationship between QoL and brace compliance. Researchers administered the Brace Questionnaire (BrQ) to 31 South African females between the ages of 13 and 16 years who had been wearing their brace for at least a year. Results of the questionnaire show that not wearing the brace as indicated by the doctor (non-compliance) was associated with poorer QoL Rivett, Rothberg, Stewart, & Berkowitz, 2009). Chan, Cheung, Luk, Wong, and Wong (2014) also found that poor compliance causes to low QoL.

Conversely, in their study of 62 adolescents who have either AIS or thoracic Scheuermann kyphosis, Korovessis, Zacharatos, Koureas, and Megas (2007) found that poorer QoL, especially in the domains of social interaction and back pain, were precursors for bracing non-compliance. Additionally, researchers found younger adolescents (ages 11 through 13 years) and males to be more compliant. The 62 adolescents completed the Quality of Life profile for the Spine Deformities Instrument to yield these results (Korovessis et al., 2007). The research of Lindemen and Behm (1999) supports the claim that poor QoL in the domain of social interaction coupled with other factors lead to low compliance in females who have AIS but suggests that the factors for low compliance in males who have AIS may appear to have high QoL in these areas. Other researchers found low back pain to be most predictive of low QoL, regardless of Cobb angle, self-image, and satisfaction with treatment (Makino, Kaito, Kashii, Iwasaki, & Yoshikawa, 2015).

Diverging from discussions of QoL and brace compliance, Zheng, Dang, Yang, Li, Zhang, Lou, He, and Wong (2018) examined QoL in adolescents who either wore brace or participated in scoliosis-specific exercise. Every six months during the study's duration, researchers collected data pertaining to the severity of the curve(s), body image, and QoL

from 24 adolescents who wore a brace and 29 adolescents who participated in the scoliosis-specific exercise program. Though both groups showed significant curve realignment, the exercise group exhibited significantly better QoL (Zheng et al., 2018). In another study that examined the impact of scoliosis-specific exercise on QoL, researchers found that QoL did not differ in regards to home-based or clinic-based interventions (Kuruet al., 2016). The location of treatment did not have a bearing on QoL, thus the presence of deformity and treatment, itself, are influential on QoL (Kuru et al., 2016). Furthermore, Monticone, Ambrosini, Cazzaniga, Rocca, and Ferrante (2014) found that active self-correction and task-oriented exercises led to better HRQoL in adolescents with mild AIS than did traditional scoliosis-specific exercises.

Furthermore, in a study that administered the SRS to a sample of 45 preoperative adolescents, researchers found that spinal deformity was a better indictor of QoL than trunk deformity (Asher, Lai, Burton, & Manna, 2002). Spinal deformity is invisible while trunk deformity is visible (Asher, Lai, Burton, & Manna, 2002). These results suggest that knowledge of the severity of deformity is more influential than visible indications of deformity (Asher, Lai, Burton, & Manna, 2002). The research of Fortin, Grunstein, Labelle, Parent, and Feldman (2016) supports the claim that trunk imbalance (i.e., deformity) is not correlated with QoL, especially in the self-image and mental health domains. Asher, Lai, Burton, and Manna (2004) also found no correlation between either spine deformity or trunk deformity and HRQoL in preoperative adolescents. This suggests that there are factors, aside deformity, experienced by adolescents who have AIS that influence QoL (Asher et al., 2004).

Ding, Liang, Qiu, Shen, and Li (2014) aimed to determine whether the amount of vertebrae fused during surgical treatment of AIS had an impact on QoL. Researchers

collected retrospective SRS, Oswestry Disability Index (ODI), visual analogue scale (VAS), and Short Form-36 (SF-36) questionnaire scores from 30 patients fused to L3 and 30 age-matched and sex-matched patients fused to L4. Results of the battery scores reveal no difference in QoL scores between patients with differing fusion levels (Ding et al., 2014).

Overall, QoL scores are similar in males and females who have AIS across treatment types and ages. Males tend to have better SRS scores in the function, pain, and mental health domains of QoL but not in the EuroQol 5-dimension-index. QoL scores in males and females who have AIS are still significantly reduced in comparison to the general population (Diarbakerli, Grauers, Danielsson, Abbott, & Gerdhem, 2019). Bunge Juttmann, Kleuver, Biezen, Koning, Been, and The NESCIO group's (2007) research backs up the claim that QoL does not significantly differ, in the long-term, across treatment types, and thus they do not make a recommendation of favoring one treatment over another.

AIS and its impact on body image. In a study that examined 137 patients from a developing country who had untreated severe idiopathic early onset scoliosis, researchers found evidence that the impairment severely and negatively impacted HRQoL and body image. To come to this conclusion, researchers split the patients into two groups – those with Cobb angles of 90-120 degrees and those with Cobb angles above 120 degrees – and designated a control group of 50 age and sex matched controls. Then, they administered the Scoliosis Research Society 22 revision (SRS-22r) Arabic version questionnaire and Body Image Disturbance Questionnaire-Scoliosis version (BIDQ-S) to both patient groups and the controls. Both patient groups had poor HRQoL and body image scores, but the group with patients who had Cobb angles of over 120 degrees had even worse scores (Soliman, 2018).

In a study that examined the effect of brace wear on the body image of 319 skeletally immature females, Schwieger et al. (2016) administered the Spinal Appearance Questionnaire (SAQ) and the Pediatric Quality of Life Inventory (PedsQOL) 4.0 Generic Scales at the start of the study and every six months for up to two years. Researchers split participants into groups based on whose AIS was managed by observation or bracing. Analysis of questionnaire responses revealed that there were not any statistically significant differences between the observed and the braced groups, meaning bracing did not have an impact on body image in their sample. Patients who switched treatment types during the course of the study (i.e. from observation to bracing or surgery; from bracing to surgery) and those who had Cobb angles greater than 40 degrees reported significantly lower body image scores than the rest of study participants. Since there was no control group, it is unclear whether the body image scores of participants were comparable to age-matched peers who do not have AIS (Schwieger et al, 2016).

Researchers in Iran did find evidence that brace wear negatively impacted body image in adolescents with AIS. Shahidi & Jannesari (2015) recruited 237 adolescents ages 12 through 18 and divided them into three groups – those who had AIS and were undergoing brace treatment, those who had AIS and were not undergoing brace treatment, and those who did not have AIS. To measure body image and QoL in this sample, researchers administered the Body Image Concern Inventory (BICI) and the Satisfaction with Life Scale (SWLS). Analysis of the questionnaire results showed that adolescents who have AIS had lower self-esteem scores, with those undergoing brace treatment having reported significantly lower QoL and body image compared to the other groups. There were no sex differences in body image scores (Shahidi & Janesari, 2015).

Sapountzi-Krepia et al. (2001) did find evidence for sex differences within body image scores. In their study, they conducted semi-structured interviews with 134 girls and 16 boys with AIS who wore Boston braces and with 99 girls and 51 boys who did not have AIS. All participants lived in Athens, Greece. Researchers used the Piers–Harris scale to take measures. Analysis of results showed that scoliosis group (girls and boys) had lower body image than controls, but boys with AIS fared better than the girls with AIS. It is also important to note that only 5% of participants with AIS reported having opportunities to discuss their feelings and concerns about their disease with professionals. Ninety percent of participants with AIS reported wanting more opportunities to discuss their feelings and concerns about their disease with professionals (Sapountzi-Krepia et al, 2001).

The studies, above, found evidence for AIS's negative effect on body image but do not say whether decreased body image is a short-term or a long-term effect. Noonan et al's (1997) analysis of females who wore Milwaukee braces as adolescents asserts it is a long-term effect, which persists at the seven-year, post-treatment follow-up they conducted.

Conversely, some researchers (e.g., Schwieger et al., 2007) did not find evidence to suggest AIS or its treatments negatively effects body image. In one study, 30 female patients who completed wearing Milwaukee Braces to treat their AIS at least 23 years before and 42 healthy, age-matched controls completed the Polish versions of the SRS-22, Spinal Appearance Questionnaire (SAQ), Bad Sobberheim Stress Questionnaire-Deformity (BSSQ-Deformity), Bad Sobberheim Stress Questionnaire-Brace (BSSQ-Brace). Results of these questionnaires were not conclusive in terms of whether or not Milwaukee bracing impacted general mental health in the long-term. (Misterska et al, 2018)

Schwieger et al. (2017) administered the SAQ and the PedsQOL4.0 to 167 skeletally immature females after six, 12, and 18 months of wearing their braces. Results of the questionnaire showed that neither the most-compliant nor the least-compliant brace wearers experienced significant impacts on their QoL or their body image. Schweiger et al use these results to suggest brace wear does not have an impact on QoL or body image. The study did not involve a control group though, so researchers did not comment on whether or not the participants' body image scores were consistent with age-matched peers who do not have AIS.

In a dissertation that examined the concept of self-esteem, the Body Esteem Scale for Adolescents and Adults (BES) determined that female adolescents who have scoliosis, treated either by brace or by surgery, exhibit higher self-esteem scores than controls. The author says these results suggest AIS improves self-esteem, though the sample was non-representative of the population (Wade, 2007).

Conversely, Zhang et al. (2011) found evidence for lowered self-esteem in their sample of 46 patients with Cobb angles larger than 30 degrees. Researchers in this study separated the patients into either the surgical group or the non-surgical group, which was comprised of participants who wore braces or whose doctors just observed their AIS progression. Researchers used scales to measure life satisfaction and self-esteem prior to treatment and about one year after treatment. Results revealed no differences in life satisfaction between the surgical and non-surgical groups prior to treatment but the non-surgical group had significantly higher self-esteem scores. Life satisfaction and self-esteem scores improved significantly for the surgical group after treatment while scores of the non-surgical group stayed this same or decreased (Zhang et al., 2011).

AIS and its impacts on socioemotional factors. Beyond examining how AIS affects the mental health of adolescents, it is important to explore other intrapersonal factors that are associated with AIS. D'Agata et al (2014) researched the personality traits of patients who have AIS. Via a cross-sectional study of 43 patients, only four of which were male, this group of researchers found that the personalities of adolescents who have idiopathic scoliosis are dominated by introversion. By the researchers' definition, introversion is characterized by self-reliance and inhibited social relationships.

In a later study, D'Agata, Sánchez-Raya, and Bagó (2017) studied personality in patients with AIS, again, but in light of HRQoL. In this study, a sample 50 patients with a mean age of 16 years completed a socio-demographic data questionnaire, the Human Figure Drawing (HFD), and SRS-22. Though D'Agata et al. found no correlation between HRQoL and personality, they found 50% of the sample had bodily and emotional tension (stress). Furthermore, the older participants were, the more likely they were to suffer stress in regards to AIS.

A study that examined the long-term impacts of Boston bracing experienced by those with AIS and late-onset juvenile scoliosis recruited 360 patients, 251 of which were female, to respond to multiple batteries 16 years or more post-brace treatment (Lange et al, 2011). Of interest for this review were the responses to SRS-22 which, when analyzed, revealed that participants who went on to have surgery after their bracing had significantly reduced self-image scores (Lange et al, 2011). Patients who had curves greater than 45 degrees at the time of the study also had significantly lower self-image scores (Lange et al, 2011). An earlier iteration of this study, which examined self-image in a sample of 137 braced patients, only seven of which were male, did not find any differences in self-image between groups (Lange,

Steen, & Brox, 2009). Ólafsson, Saraste, and Ahlgren (1999) did not find that bracing, alone, affected self-image, either.

In a study that examined HRQoL in 110 Korean adolescents with AIS, researchers found that HRQoL did not differ significantly based on Cobb angle, but self-image did. Analysis of the SRS-22 results from the participants revealed that earlier age at diagnosis and undergoing conservative treatment generally related to better HRQoL. Adolescents who had curves greater than 40 degrees had the lowest self-image scores, followed by those who had curves between 25 and 40 degrees, and finally by those who had curves between 10 and 25 degrees. Researchers did not discuss how these scores related to an age-matched population that does not have AIS (Lee, Choi, Jin-Ho, & Park, 2016).

Another set of researchers examined self-image and QoL between participants who had AIS and were undergoing observations and participants who had AIS and were undergoing bracing. Forty-six participants in each group filled out the SRS-22. Researchers analyzed the results of the SRS-22 and found that the braced group had significantly worse QoL scores, especially in the self-image domain. This suggests that wearing a brace negatively impacts self-image in those who have AIS (Cheung, Cheng, Chan, Yeung, & Luk, 2007).

Self-concept is closely related to the topic of self-image and is also impacted by AIS and its treatments. Zhang, Wang, Chen, Gao, Yu, Sun, and Li (2011) measured the self-concept of 65 adolescent patients using the Children's Self-Concept Scale at the beginning of treatment and one year later. Twenty-two patients (Cobb angles between 20 and 40 degrees) participated in conservative treatment, 18 patients (Cobb angles between 40 and 50 degrees) participated in conservative treatment, and 25 patients (Cobb angles between 40 and 50

degrees) received surgical treatment. The initial measure of self-concept revealed higher scores in the patients who had curves between 20 and 40 degrees. Follow-up measures showed that the self-concept of surgical patients improved, and the self-concept of conservatively treated patients declined. This means conservative treatment negatively impacted self-concept while surgery improved it (Zhang et al., 2011).

Another aspect of socioemotional health that AIS and its treatments can affect is social interaction. At least 20 years after the completion of treatment, a team of researchers administered multiple batteries and their own set of study questions to 145 females and males who wore braces to treat their AIS. The batteries measured various aspects of mental health and HRQoL. Analysis revealed no significant differences between the mental health scores of participants who had AIS and the controls who did not have AIS, but participants did admit to limiting their social activities. Their reasons for limiting social activities included difficulties in physical participation and being self-conscious about their appearance. These results suggest that AIS has long-term social effects, specifically in those who wear braces (Danielsson, Wiklund, Pehrsson, & Nachemson, 2001).

In interviews conducted by Honeyman and Davison (2016), female adolescents who have AIS expressed reservation in divulging their feelings about their diagnosis to friends, family, and professionals involved in their care. This is another aspect of social inhibition that makes patients even more vulnerable to emotional instability (Honeyman & Davison, 2016).

In a study that examined brace wear on personality in female adolescents who have AIS, researchers found that the personalities, and thus the socialization and stress reactions, of their sample changed throughout the course of treatment. Researchers used the Maudsley

Personality Inventory to come to this conclusion. They use this information to encourage professionals to modify brace treatment based on the personalities of patients to promote better outcomes (Matsunaga, Hayashi, Naruo, Nozoe, & Komiya, 2005).

Andersen, Andersen, Thomsen, and Christensen (2002) similarly found brace treatment to be a hindrance to social activities. The responses of 136 patients who had AIS and wore a Boston brace revealed 54% refrained from activities they normally would have participated in, 23% gave up participating in sports, 13% experienced harassment from peers because of their brace, and at three-and-a-half years post-treatment, 13% said they were still reserved around the opposite sex because of their brace treatment (Andersen et al., 2002). Piantoni et al. (2018) add to the discussion of AIS's impact on social activities with their sample's self-reports. Fifty-four percent of the sample reported feeling as if their bracing treatment for AIS impacted their socialization and 40% reported conflicts in school as a result of their treatment (Piantoni et al., 2018). Payne et al. (1997) also found evidence for AIS's impact on social interaction and further asserts that gender differences exist in these and other health-compromising behaviors.

AIS and its impact on depression. Another aspect of mental health analyzed in the literature concerning AIS is depression. Płaszewski et al. (2014) performed a cross-sectional study with retrospective data collection to analyze the mental health and QoL in 43 women who were treated for mild to moderate AIS (11–36° Cobb angle) an average of 16.5 years prior. Of their measures, the Beck Depression Inventory (BDI) is of interest to this thesis. Analysis of BDI responses revealed depressive symptoms in the sample, with those who had milder Cobb angles exhibiting more depressive symptoms (Płaszewski et al, 2014). Chang et al. (2016) also found evidence for depression in a cohort of patients with idiopathic scoliosis

after collecting data for five years. The study cohort consisted of males and females. Data analysis revealed that the patient sample had a higher incidence rate of depression than controls, especially when patients were younger (adolescents) and/or male (Chang et al, 2016). In an earlier study, researchers found evidence for depression in their sample of 95 women treated with a Milwaukee brace in adolescence, 30 of whom went on to have surgery. This study is unique compared to the previous two because it asserts depression found in the sample resolved sometime within the seven years between the end of treatment and the study's follow-up measures (Noonan et al, 1997).

AIS and its impact on anxiety. In addition to body image, researchers have also studied anxiety in patients who have AIS. Glowacki et all (2013) recruited 36 female adolescents who wore Cheneau brace and received treatment from the same center for their study. Participants filled out STAIC-trait and SAQ-pl questionnaires at the start of the study and again six and 12 months after the study began. The first set of measures revealed 16.6% of participants experienced high anxiety while most (83.4%) experienced low or medium anxiety. Both the second and the third set of measures revealed 8.3% of participants experienced high anxiety while most (91.7%) experienced low or medium anxiety.

Psychological Outcomes of Surgery. Much of the literature examined post-surgical outcomes of patients who had AIS. Rodrigues, Gotfryd, Machado, Defino, and Asano (2017) focused their study on peri-operative factors and post-operative outcomes measured in SRS questionnaires. Rodrigues et al. (2017) found that all domains of SRS scores improved after surgery, but that satisfaction scores were higher in those who underwent surgery after 15 years of age. Patients who wore braces prior to surgery showed less improvement in overall scores than those who did not wear braces and males had significantly higher mental health

scores than females (Rodrigues et al., 2017). The results of Yu, Wang, Qiu, Shen, and Zhang's (2016) study dispute the claim that brace wear prior to surgery resulted in less improvement in post-op scores. According to their study, which utilized two batteries, brace wear prior to surgery had no bearing on post-op mental health scores (Yu et al., 2016).

Bago, Perez-Grueso, Pellise, and Les (2012) administered the SRS to a sample of 71 females and 14 males who underwent spinal fusion for AIS and found that not all scores met the minimal detectable change, which is the level of score improvement after surgery considered successful. Members of the sample were similar in age, number of fused vertebrae, and curve magnitude. Patients who met the minimal detectable change had worse pre-op scores in pain, perceived body image, mental health, and subtotal than patients who did not meet the minimal detectable change. Patients who did not meet the minimal detectable change had better pre-op scores in these domains. These results suggest that those who have AIS and experience salient struggles because of it prior to spinal fusion benefit more from the procedure (Bago et al, 2012). Sieberg, Manganella, Manalo, Simons, and Hresko (2017) also found evidence to support the idea that worse pre-operative factors in the domains of mental health and pain lead to better post-surgical outcomes.

Chaib et al. (2013) also looked at post-operative SRS scores. They mailed the French version of the SRS to 45 patients who underwent spinal fusion surgery for AIS at least two years prior. Scores for function and self-image were comparable to controls who did not have AIS but pain and mental health scores were significantly lower than those of controls (Chaib et al., 2013). Conversely, Akazawa, Minami, Kotani, Nemoto, Koshi, and Takahashi (2012) found spinal fusion to have no adverse effect on pain and mental health scores, but did result in lower self-image.

Ward et al. (2017) warn against routine surgical treatment for AIS because their study revealed no statistical difference between the SRS scores of their non-surgical group and their surgical group at an average of eight years post-treatment.

Benli et al. (2007), too, used the SRS to measure post-operatives outcomes. A sample of 109 participants who underwent surgical treatment for AIS filled out the SRS at least 10 years after their surgery. Analysis of their SRS answers revealed that surgery had a positive effect on SRS scores, especially in the domains of self-image and mental status (Benli et al., 2007).

Additional work also supports the claim that spinal fusion surgery leads to improved mental health outcomes for adolescents with AIS (Duramaz et al., 2018; Iida et al. 2015; Koch et al., 2001; Manalo, 2014; Marrache et al., 2019; Misterska, Głowacki, & Harasymczuk, 2011; Rocha Rodrigues et al., 2015; Simony, Hansen, Carreon, Steen, & Mikkel, 2015; Smucny, Lubicky, Sanders, Carreon, & Diab, 2011; Zebracki, Thawrani, Oswald, Anadio, & Sturm, 2013). The research of Roberts et al. (2011) qualifies these claims with evidence that the improvements are larger in males than in females.

Other. This section presents the literature that does not fit into one of the categories already defined. The literature presented evidence against an increased prevalence of eating disorders (Zainaet al., 2013) and against bracing's impact on emotional reactions (Beka et al., 2006) in patients who have AIS.

Morse et al. (2012) studied the impact of culture and ethnicity on post-op outcomes for patients who have AIS. Researchers collected SRS scores from 1,853 adolescents who were U.S. White (1,234), Black (213), Hispanic (78), and Asian (29), native Japanese (192)

or Korean (107). Morse et al. (2012) found significant differences between groups in pain, appearance, activity, and mental health after researchers adjusted for age, sex, curve magnitude, and BMI. These results emphasize the necessity of culturally competent and individualized care (Morse et al., 2012).

In an attempt to improve treatment for AIS, Negrini, Grivas, Kotwicki, Maruyama, Rigo, Weiss, and the members of the Scientific society On Scoliosis Orthopaedic and Rehabilitation Treatment (SOSORT) (2006) performed a multifaceted study, which identified multiple reasons to treat AIS. Some of the most important reasons identified and that relate to this thesis were aesthetics (related to body image), QoL, and psychological well-being. This study shows that the needs and wants of patients are not always the same ones perceived by professionals, but research can lead to increased knowledge and a closer alignment between the needs of patients and their care plans (Negrini et al., 2006).

AIS and its impact on parents. Thus far, the literature has focused on the effects AIS has on patients but Wang et al. (2019) examined parental psychological health, as did Misterska, Glowacki, Adamczyk, and Jankowski (2014). Wang et al (2019) administered the Patient Health Questionnaire (PHQ-9) and the Generalized Anxiety Disorder 7-item scale (GAD-7) to 64 Chinese patients with scoliosis and 85 of their parents. Analysis of questionnaire answers showed that both patients with AIS and their parents display levels of anxiety and depression that are significantly higher than healthy controls (Wang et al, 2019).

Misterska et al. (2014) sought to determine the difference in perceptions of body image between Polish patients who have AIS and their parents. To do so, researchers administered the Polish version of the SAQ to 41 pairs of female patients who have AIS and wore a Cheneau brace at the time of the study and one of their parents. The scores of patients

and their parents closely mirrored each other and revealed they were the most critical of body shape and waist asymmetry. This study did not say whether the patients who have AIS and their parents were comparable to those who do not deal with AIS. Researchers also made it a point to warn against the generalization of the results to the AIS populations in other countries since Poland's social situation regarding disabilities is different from that of developed countries (Misterska et al, 2014)

Glowacki et al. (2013) led a similar study in which patients who had AIS and their parents filled out Polish versions of the Strengths and Difficulties Questionnaire-25 (SDQ-25) to determine how they perceived patient mental health. Analysis revealed that patients and parents generally perceived the patient's mental health in the same way. There were areas of concern, but psychiatric disorders were unlikely. Those who had poorer psychological outcomes had more severe cases of AIS. Brace-wear duration and age also affected psychological outcomes (Glowacki et al., 2013).

Misterska, Glowacki, and Latuszewska, (2012) found patient and parental perceptions of stress that were in line with previous assertions that patients who have AIS experience moderate brace related stress and low deformity related stress. In their study of 63 pairs of female patients and parents, perceptions of brace relate stress were similar. Parental perception of stress differed in that they tended to overestimate their adolescent's deformity related stress (Misterska et al., 2012).

Ugwonali et al. (2004) also studied patient and parental perceptions but on QoL rather than stress or mental health. A sample of 78 adolescents who had AIS and were undergoing brace treatment and their parents self-reported QoL. Analysis of these reports revealed no decrease in QoL in the AIS sample compared with observed counterparts.

Parental response in Sanders et al.'s (2018) study did not closely reflect their adolescent's true experience with clinically significant psychological and emotional problems. Patient responses to the BASC-2 revealed 32% of the patient sample experience clinically significant psychological and emotional problems. Only 34% of parent responses to the BASC-2 matched these findings which means 66% of parents were unaware of the clinically significant psychological and emotional problems their adolescent experienced.

Donnelly, Dolan, Grande, and Weinstein (2004) conducted a study that analyzed the effects of bracing for AIS on both patients and parents. In this focus-group based study, parents were able to speak on their own challenges rather than convey their perceptions of their adolescent's challenges. Analysis of responses showed that while patients and parents might not experience pathological issues, they did experience stress in many domains (Donnelly et al., 2004). The research of MacLean, Green, Pierre, and Ray (1989) echoes these findings.

Research Question A Results. The literature presented evidence for AIS's effect on eight domains of psychological health. Domains included stress, impacts on general QoL or HRQoL, impacts on general mental health, decreased body image, introversion and social issues or inhibition, altered self-image or self-concept, depression, anxiety, and "other." The "other" domain included effects that did not fit into one of the clearly defined domains, including personality changes, clinically significant psychological difficulties that researchers did not otherwise specify, shock/fear/worry, and suicidal thoughts. The literature presented the most evidence for the stress domain, with 16 occurrences. Table 5 presents the number of occurrences for each effect domain.

Table 5

Psychological effects of AIS

Effect	Number of Occurrences
Stress	16
(General) QoL or HRQoL	11
(General) Mental Health	9
Decreased Body Image	8
Introversion/Social Issues or Inhibition	8
Altered Self-Image/Self-Concept	7
Depression	4
Anxiety	3
Other	4

In addition to the information presented in the chart above, it is important to note that only seven studies included parents or guardians in the research on the psychological effects of AIS and its treatments. Four of these studies measured parental perception of psychological effects on their adolescent, without determining the psychological effects parents experienced, themselves. Zero studies examined the effect of an adolescent's diagnosis with and treatment for AIS on siblings.

Research Question B

B.) How can Certified Child Life Specialists support the treatment of AIS for adolescents and their families?

CCLS complete education and training that enables them to implement interventions in a variety of medical contexts in order to support and strengthen the resilience of patients

and their family systems. The following section of review presents an overview of contexts in which CCLS often work.

Roles. This section of review presented CCLS interventions in the contexts of pre-op (Beickert & Mora, 2017; Brewer, Gleditsch, Syblik, Tietjens, & Vacik, 2006; Osborne, 2018), the emergency room (Koch, 2015; Martin, 2017; Sanchez Cristal et al., 2018), orthopaedics (Schlechter, Avik, & DeMello, 2017), oncology (Gormley, 2017; Ruhl, 2016), radiology (McGee, 2003; Metzger, Mignogna, & Reilly, 2013), inpatient units (Kirkenbauer, 2013; Koch, 2015; Trapp, 2015), and the Neonatal Intensive Care Unit (Smith, Desai, Sira, & Engelke, 2014).

CCLS are educated and clinically trained professionals whose practice emphasizes play experiences and expressive outlets, developmentally appropriate deliverance of medical information, and building therapeutic relationships with patients and their families (ACLP, n.d. A; ACLP, n.d. B; Committee on Hospital Care, 2000; Cooper, 2016; Kung, 2016; Ruhl, 2016; Wyles, 2008). Their goals are to focus on the strengths of patients and families, promote optimal development, and minimize adverse effects of the hospital experience (ACLP, n.d. A; ACLP, n.d. B; Committee on Hospital Care, 2000). CCLS implement interventions based on the unique needs of the individual and/or family (ACLP, n.d. A; Committee on Hospital Care, 2000).

Since CCLS have knowledge of the medical field and developmental and psychological needs, it is beneficial to include them in the delicate process of disclosing diagnoses to patients and families. In a study that examined the role of CCLS in diagnosis disclosure, 85% of surveyed CCLS reported that they saw benefits to being involved. The most reported benefits included being able to provide developmentally appropriate

explanations, psychosocial support, education, and assessment for patients and families (Garcia, 2015).

A common role for CCLS to take on is pre-operation preparation and distraction to reduce pre-op anxiety, reduce pain, and increase procedure effectiveness and patient satisfaction (Beickert & Mora, 2017; Osborne, 2018;). Methods of undertaking this task include but are not limited to the use of technology such as tablets and virtual reality devices (Osborne, 2018), medical dolls, children's literature, photos, videos, deep breathing, guided imagery (Beickert & Mora, 2017), and blowing bubbles (Martin, 2017). In study that examined Child Life intervention in Day Surgery, researchers found, via the "Child Drawing: Hospital" instrument, school age children who received an intervention from a CCLS showed significantly less anxiety than school age children who did not receive and intervention from a CCLS (Brewer et al, 2006).

Many of the same methods mentioned above are useful in general procedural preparation and distraction, too (Beickert & Mora, 2017). To prepare for procedures during which the child will be fully awake and aware, such as IV insertion, laceration suturing, and medical imaging, it may also be helpful to show children all the tools that will be involved and explain their uses to reduce feelings of uncertainty (Martin, 2017; Metzger et al, 2013; Sanchez Cristal et al, 2018). This process is known as normalization (Koch, 2015). In a study that examined Child Life intervention before and during IV placements, researchers found distraction techniques were only helpful in reducing stress in patients two through seven years of age (Lofgren, 2015). Through all of these methods, CCLS should be providing detailed, accurate, developmentally appropriate information (Beickert & Mora, 2017; Gooden, Lowrie, Jackson, Mitchell, & Tatem, 2018; Metzger et al, 2013).

CCLS play a critical role in the support of family members, too. In a study that examined the CCLS role in supporting those with firearm injury and trauma, Koch (2015) revealed that family members of the child or adolescent who was shot pursued emotional support from CCLS. In a study that asked CCLS to self-report the tasks performed in the NICU, researchers found that parental and sibling support was the most common (Smith et al, 2014). Family support is also beneficial in less high-risk contexts, like when a child is undergoing imaging. Metzger et al (2013) emphasized the need for CCLS to assess parental knowledge of and feelings about the imaging process so they could be active participants in their child's coping. Interventions that provide psychological preparation and emotional support to family members are so important because they instill each family member with the confidence that they can manage the medical challenges they face (McGee, 2003).

Researchers also presented findings that reveal CCLS are equipped to address chronic pain in adolescents (Kirkenbaurer, 2013), resistance to treatment compliance in adolescents (Carter, 2014), and stress, depression, and QoL in pediatric cancer patients (Gormley, 2017)

These outlined roles of CCLS are should not be taken on in isolation from the rest of the care team. CCLS are interdisciplinary (multidisciplinary) team members who assist other professionals in reaching their care goals for patients and help educate team members about the developmental and psychological needs to patients and families (Diaz, 2019; Drayton, Waddups, & Walker, 2019; Gooden et al, 2018; Koch, 2015; Lee, 2018). Barriers to the efficacy of Child Life intervention include staff availability, space availability, time availability, and staff workload (Osborne, 2018).

Resilience. The CCLS approach to care and support strongly links with strategies that promote resilience in patients and their families (Humphreys & LeBlanc, 2016). Assessment

allows CCLS to understand where a patient and family is coming from and how well they are coping (Humphreys & LeBlanc, 2016). To promote resilience, it important that assessments focus on the strengths of patients and families over their needs or deficits (Michel, 2016). The individualized interventions CCLS implement after assessment serve to reinforce factors that lead to resilience, minimize factors that undermine resilience, teach new coping mechanisms, and connect patients and families to resources that optimize their resilience (Humphreys & LeBlanc, 2016). It is especially helpful if these interventions seek to increase family cohesion, reduce family conflict, and address stress in as many members of the family system as possible, which allows them to scaffold each other's resilience (Michel, 2016)

In a study that examined resilience programming facilitated by a CCLS in a sample of pediatric patients who have cancer, researchers found Promoting Resilience in Stress Management (PRISM) increased cancer-related QoL. PRISM incorporates three sets of resources that can help manage adversity, including internal resources for stress management and mindfulness skills, community resources for social support, and existential resources for the search for meaning-making. At the end of this study's programming, most patients and guardians decided to share what they learned in a family de-briefing session so they could learn from each other and work on building resilience, together. (Gormley, 2017).

A phenomenological study that examined parental perceptions of CCLS impact on family stress and resilience, Bell (2015) found that parental units who were interviewed showed a strong understanding of the services CCLS provide and assessed them as efficacious in assisting with family stress and promoting resilience. Two out of three parental units said that the medical stressors they experienced strengthened their families. From these

statements, the researcher inferred that CCLS played role in the families' resilience (Bell, 2015).

In a study that examined parental satisfaction with CCLS interventions, researchers defined CCLS as "trained professionals whose job is to help children cope with being in the hospital and with other stressful events" (LeBlanc, Naugler, Morrison, Parker, & Chambers, 2014, p. 258) and stated that the goal of CCLS intervention was to build resilience. A range of 90% to 100% of parents reported being satisfied with the CCLS interventions they and their children received, but researchers did not measure how their satisfaction related to resilience (LeBlanc et al, 2014)

Research Question B Results. The literature review for this section discussed the roles and responsibilities of CCLS in a variety of medical contexts. None of the literature explicitly described CCLS in relation to AIS. Nonetheless, all but one of the roles and responsibilities translate into the experience with AIS. The role that does not translate into the experience with AIS is emergency room support. Table 6, below, presents all of the roles and responsibilities of CCLS identified in the literature review and gives examples of them in the context of AIS. CCLS perform all of these roles in an attempt to minimize stress and maximize resilience for the patients and families they work with.

Table 6

Identified Roles of Child Life Specialist and their Application to Experiences with AIS

Roles/Responsibilities	Application to Experiences with AIS
Interdisciplinary Team Member	Communicate with orthopaedist, orthotists, nurses, and other team

	members involved with AIS treatment
Assessment	Assess the developmental and psychological needs of each AIS patient and family
Diagnosis Disclosure	Assist orthopaedists in disclosing the diagnosis of AIS in developmentally and psychologically appropriate ways
Build Therapeutic Relationships	AIS observation and treatment is often long term. CCLS can introduce themselves to patients and families at diagnosis and continue to see them throughout the course of treatment.
Psychological Support	AIS diagnosis and treatment contribute to psychological effects (stress, anxiety, depression, body image issues, and more). CCLS can assist patients and families in addressing these effects.
Provide Family Support	Adolescents diagnosed with AIS are part of a family system. CCLS can assess and respond to the needs of all family members they encounter.
(General) Procedure Preparation and Distraction	CCLS can provide developmentally and psychologically appropriate explanations of and distraction from procedures during the course of treatment for AIS.
Pre-op Preparation and Distraction	Some patients with AIS need to have spinal fusion surgery. CCLS can assess the patient's and family's understanding of the surgery, fill in gaps in knowledge,
Radiology Support	AIS requires doctors to take x-rays of the adolescent's back. Some adolescents may not be familiar with the x-ray process so CCLS can explain (and show) what it will be

	like and what is expected from the adolescent.
Orthopaedic Support	The measuring and fitting of braces can be stressful for patients and families. CCLS can provided distraction and assist with coping mechanisms during the process.
Emergency Room Support	N/A
Support Treatment Compliance	Brace effectiveness is largely dependent on the patient's compliance with their doctor's recommendation for wear. CCLS can address the concerns of adolescents have about the brace and provide them with coping mechanisms to encourage them to wear the brace.
Provide Play Opportunities	CCLS can provide play opportunities to AIS patients and their families while they are waiting for appointments or while they are in the hospital after spinal fusion surgery.
Aid in Pain Management	CCLS can provide instruction on techniques (such as mindfulness) that distract from or alleviate pain caused by the physical deformity of AIS or by the treatments of AIS.

Research Question C

C.) How does psychological support currently available improve the outcomes and care for AIS patients?

Not much literature explicitly connecting AIS and the Child Life profession is available. The literature that is available centers on Child Life interventions surrounding spinal fusion surgery for the correction and stabilization of scoliotic curves. This section of

the paper presents two cases of face-to-face CCLS interventions and two resources created with the help of CCLS.

Face-to-Face Intervention – Case Study. Sorensen, Card, Malley, & Strzelecki (2009) presented a case study in which a 12-year-old female, Melissa, and her parents receive face-to-face intervention from multiple CCLS. The interventions for this case focused on familiarization with the hospital environment, assessment of and addition to procedural understanding, assessment of affect towards procedure, and figuring out effective coping mechanisms. Melissa first interacted with a child life specialist at her preoperational appointment whereas her parents had a prior telephone consultation. During Melissa's initial meeting, a CCLS who used a picture book to supplement preparation answered her questions. After setting Melissa up with an art activity, the CCLS spoke to other team members who would be involved with the surgery to relay Melissa's concerns and get answers for questions not previously answered. Melissa had to have a blood test that day so the CCLS talked her through the process prior to it happening and gave her the option of watching the blood draw or using a distraction. She chose to look at an I-Spy book and the CCLS reminded her to take breaths during the blood draw.

After that portion of the pre-op appointment, the CCLS arranged a hospital tour and introduced Melissa and her parents to CCLS on other units who would interact with them on the day of, and the days following, Melissa's spinal fusion. During these introductions, a group of CCLS passed along Melissa's fears and concerns so they could create a shared coping plan. In the process, Melissa saw an empty post-op patient room and the activity room she would have access to and the CCLS encouraged her to bring comfort items with her on the day of surgery. (Sorensen, Card, Malley, & Strzelecki, 2009)

On the day of surgery, Melissa and her parents initiated coping strategies practiced at the pre-op appointment. The CCLS met with Melissa to discuss what she was feeling and to reassure her that she was going to be safe and taken care of. After the surgery, Melissa was assigned an inpatient CCLS who would assist her through admission. The CCLS communicated information about Melissa's preferred coping mechanisms and means of interacting to the interdisciplinary team in charge of her care. The CCLS also provided Melissa and her parents with a schedule outlining procedure times, activities, and events that would happen during her admission. When Melissa felt up for it, the CCLS engaged her in developmentally appropriate activities. (Sorensen, Card, Malley, & Strzelecki, 2009)

At a follow-up appointment that took place after Melissa's discharge from the hospital, she visited with the inpatient CCLS and communicated that the hospital experience was a lot better than she expected it to be. Melissa's parents conveyed their appreciation for the family-centered approach at support and comfort implemented during her hospitalization. (Sorensen, Card, Malley, & Strzelecki, 2009)

Face-to-Face Intervention – Hospital Tours. In the other face-to-face spinal fusion intervention reported in the literature, CCLS and/or an orthopaedic nurse practitioner led patients and their caregivers on a 30-minute hospital tour, standardized by script and objectives, prior to admission for the procedure. Researchers randomly assigned patients between 11 and 21 years of age scheduled for spinal fusion surgery to correct AIS to either the control group or the intervention group. Both groups had pre-op visits with their surgeons, but only the intervention group received the hospital tour in which professionals additionally encouraged them to ask questions. A CCLS or an orthopaedic nurse practitioner administered The State-Trait Anxiety Inventory (STAI) and the State-Trait Anxiety

Inventory for Children (STAI-C) at the patients' preoperative appointment, immediately preoperative, postoperative, and at discharge to determine both the patients' and their caregivers' levels of anxiety surrounding spinal fusion. Additionally, researchers administered the battery to caregivers while their child was in surgery. Results of the STAI and STAI-C do not show significant difference between the anxiety of the control group and the anxiety of the intervention group, except for during the postoperative period in which the intervention group scored higher in state anxiety. Researchers also administered a satisfaction survey that used a Likert Scale to measure various experiences surrounding the spinal fusion from least satisfied (0) to most satisfied (4) on the day of discharge. Results of the satisfaction survey showed significantly higher patient satisfaction in the intervention group and higher caregiver satisfaction that neared statistical significance in the intervention group. Researchers did not perform separate analyses of the STAI, STAI-C, and satisfaction batteries based on which professional(s) facilitated the hospital tour. (Rhodes et al., 2014)

CCLS-Created Resources for Intervention. The other literature that connected AIS and CCLS, in contrast, focused on resources created by CCLS to aid in preparation for spinal fusion surgery rather than face-to-face interventions (e.g., Macculloch et al,, 2010). These interventions also attempted to familiarize patients with hospital environments and procedures and provided important information but were not tailored to each unique patient's and family's needs. One of these studies developed from the results of a needs-assessment conducted to determine the needs of patients and families facing spinal fusion for AIS in an online informational platform. Two focus groups of five and six members, each, included three registered nurses, two physiotherapists, two orthotists, an orthopaedic surgeon, a nurse practitioner, a social worker, and a child life specialist. After two facilitators posed questions

and gathered information from patients and families, clinicians proposed four guidelines for creating a relevant internet resource:

> (1) create the website with the target audience in mind; (2) clearly state the purpose of the website and organize website content to support the user; (3) offer a professionally-moderated interactive support component; and (4) ensure accessibility of website information and support by considering the age, gender, reading level and geographic location of potential users, (Macculloch, Nyhof-Young, Nicholas, Donaldson, & Wright, 2010, p.1)."

Of the last two articles connecting CCLS and AIS, one was a re-analysis of the first, which assessed the effectiveness of informational videos developed, filmed, and delivered by a CCLS on reducing postoperative anxiety and pain. Researchers split participants, who ranged in age from 11 to 18 years old, into four groups. Depending on the assigned group, participants watched a video containing concrete-objective information plus coping instruction (n= 30), concrete-objective information only (n= 27), or coping instruction only (n= 27) on the day of their pre-op appointment. Participants who received coping instruction, with or without concrete-objective information, practiced the techniques with the researcher after viewing the video. The fourth group was the control (n= 25) and watched no instructional video. The STAI-C was used to measure patient anxiety prior to surgery and again on day two post-op. A Visual Analog Scale (VAS) with a continuous scale from 0 (no pain) to 10 (worst pain ever) was used to measure patient pain on day two and day four post-op. Analysis showed that the concrete-objective information plus coping instruction intervention was significantly more effective at reducing post-op anxiety than the other interventions and the control. The most significant factor in reducing pain was the duration of

time from day two to day four. Analysis revealed interventions with coping instruction yielded a reduction in pain that was significantly different from that of the concrete-objective information, only, and control groups only for adolescents 11 through 14 years old. (Lamontagne, Hepworth, Cohen, & Salisbury, 2003 A).

In a follow-up study, researchers reanalyzed pain data, only, from the subsample of young adolescents. They also ran analyses that looked at day two pain ratings and day four pain ratings, individually. Results show the effect of coping instruction, only, on pain reduction was statistically significant on day two and day four. Additionally, coping instruction with concrete-objective information resulted in a statistically significant pain reduction on day four. (Lamontagne, Hepworth, Cohen, & Salisbury, 2003 B)

Research Question C Results. Of the five sources that presented connections between AIS and CCLS, all of them reported on interventions for spinal fusion surgery. Two of these interventions were face-to-face, one was an informational website created by an interdisciplinary team including a CCLS, and two described the same informational video created by CCLS. The second of these two articles was a reanalysis of the first.

In the first intervention, CCLS gave the patient and her family information about the surgery and expected recovery, familiarized them with the hospital, and taught them coping mechanisms. At a follow up, the patient communicated that the hospital experience was "a lot better" than she expected it to be and her parents conveyed their appreciation for the family-centered approach at support and comfort implemented during their daughter's hospitalization. In the intervention that describe a CCLS-led hospital tour, patients did not experience lower anxiety than controls. They did express higher satisfaction than the control group, though. In the third source that describe CCLS involvement in surgical interventions

for patients with AIS, professionals focused on familiarizing patients and their families with the hospital environment and provided important information about the procedure and expected recovery. Researchers have yet to research the effect(s) this intervention had on patients and families.

The last two pieces of literature for this section describe videos developed by CCLS to show to patients who were preparing for surgical correction of AIS. The videos gave coping instruction, concrete information about the procedure, or coping instruction and concrete information. The patients who viewed the video with coping instruction and concrete information experienced the lowest levels of post-op anxiety in the sample. The patients who viewed the video with concrete information experienced the most pain reduction on day two and day four post-op. The patients who viewed the video with coping instruction and concrete information experienced similar pain reduction, but only on day four post-op

From these results, it seems as if CCLS most frequently support patients who have AIS and their families by increasing their knowledge of procedures and hospital environments and by helping them develop coping mechanisms. These results also show CCLS as capable of increasing comfort and satisfaction and decreasing anxiety and pain in patients who underwent spinal fusion surgery and their families.

Chapter V: Discussion

The purpose of this thesis was to examine existing literature in order to understand the psychological impact AIS has on adolescents and their family systems. Since this thesis utilized a Family Stress Theory framework, it was important to make note of where the literature included family members and where it excluded family members. This thesis also aimed to examine how CCLS can be used in intervention and support for AIS. The literature indicated a large range of psychological effects from AIS and its treatments that CCLS can effectively address. These effects include but are not limited to stress, decreased QoL and mental health, body image concerns, and social issues. Stress was the most frequently evidenced psychological effect of AIS, which further validated the decision to view AIS diagnosis and treatment through Family Stress Theory and its ABCX models. The following model inserts examples of potential experiences with AIS into an ABCX model as a way to illustrate that resilience, rather than stress and crisis, can characterize experiences with AIS.

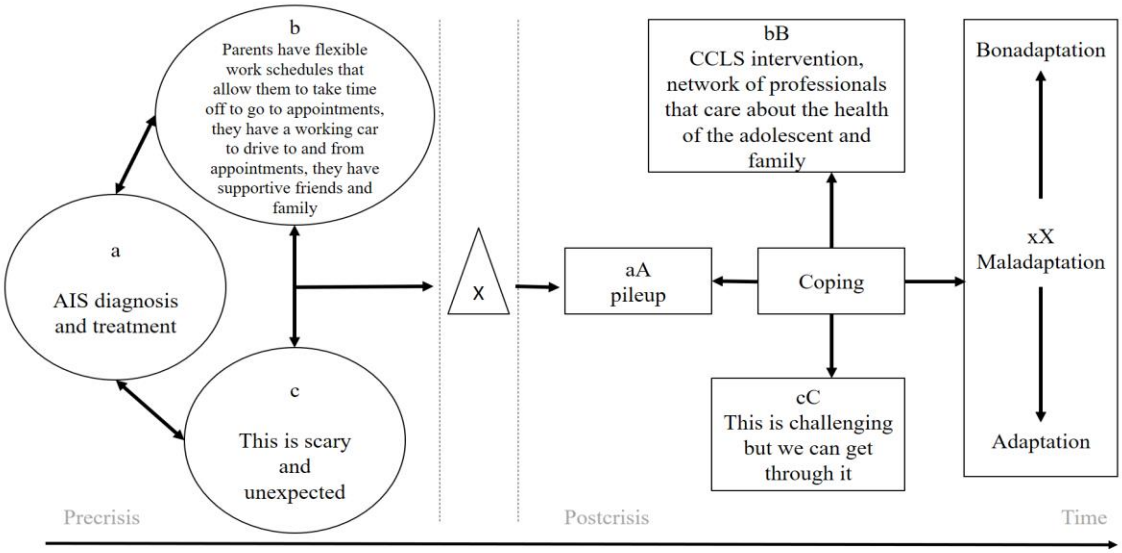

Figure 2. Double ABCX model exemplifying AIS

Within the examined literature, there were multiple instances of discussion surrounding CCLS and Family Stress Theory, since CCLS are trained to support patients *and* their family system. The literature identified 13 roles and responsibilities of CCLS. All of these roles and responsibilities except for one (emergency department support) are applicable to typical experiences with AIS. The model below exemplifies instances in which CCLS can be involved in AIS care plans.

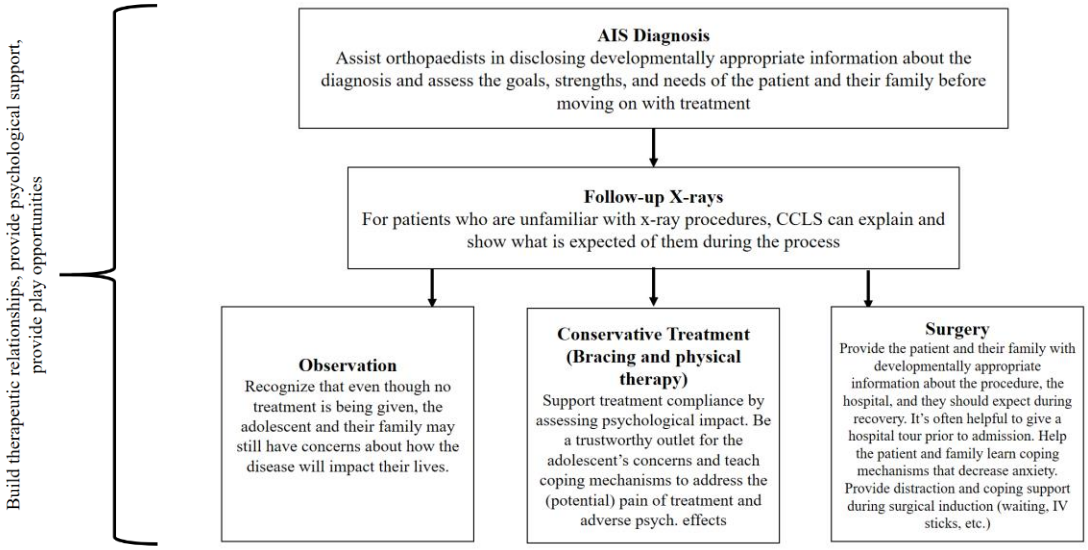

Figure 3. Examples of how to incorporate CCLS into AIS care plans

Implications

There is not consensus within the literature on the exact statistics of prevalence and severity of the psychological effects from AIS, but it is clear that there is a relationship between AIS, its treatments, and psychological health. The range of effects and severity of effects experienced by those who have AIS seem to be dependent on patient characteristics – including but not limited to personality, culture, sex, and curve magnitude – and treatment trajectory. This means professionals should treat each adolescent differently. Though this

large amount of variability presents challenges for those making decisions regarding the treatment and care of patients with AIS, CCLS are trained to make multifactorial assessments and implement interventions based on strengths, needs, and goals. These interventions decrease negative effects of diagnosis, disease, and treatment on patients and family systems and promote resilience. CCLS can also help educate other professionals on the psychological impacts of AIS and its various treatments so they can make fully informed recommendations to their patients.

Furthermore, not all patients have the knowledge, time, or money to locate psychological services, themselves, so professionals involved with the (physical) treatment of AIS should not expect them to do so. Professionals could refer patients and families to support groups or psychologists, but those endeavors likely involve additional time and money for travel. CCLS are the most efficient and effective psychological support for patients and families dealing with AIS because they are not billed separately from the medical institutions for which they work. Additionally, since they are not separate entities, they can perform interventions within the time of treatment appointments and admissions.

Limitations and Strengths

A limitation of this thesis is that the literature collected and reviewed employed many different measurement techniques. This lack of standardization made drawing concrete conclusions difficult. Additionally, much of the literature collected and reviewed utilized small samples that were not always representative of the AIS population. This also made drawing conclusions and making generalizations about the psychological effects of AIS challenging.

A strength of the literature review method employed in this thesis is that it covered a wider range of topics than a thesis that worked directly with the target population would have been able to cover. Empirical studies must receive IRB approval and work with a sample that is available to them, even if it does not meet their ideal requirements, and thus are much more limited in scope. The information gathered for this thesis was not limited to one sample demographic so the results span across cultures and sexes.

Another strength is that this thesis presented a new solution (CCLS intervention) to a problem (negative psychological impacts of AIS) while drawing on existing theories and models (Family Stress Theory and the Double ABCX model). This provides validity to the solution.

Future Direction

More researchers need to analyze the psychological effects of AIS and its treatments. Specifically, future researchers who study the psychological effects of AIS should try to recruit large, representative samples and examine AIS's impact on parental psychological health. As evidenced by the five pieces of literature retrieved from the Connections search, researchers also need to look more at CCLS involvement and efficacy in working with patients and families who deal with AIS.

Professionals involved with the treatment and care of patients who have AIS do not need to wait until there are definitive, standardized results to start making changes in AIS care plans, though. Orthopaedists, orthotists, and physical therapists can use the evidence within this thesis to assert the need of psychological support in AIS treatment and make a case for CCLS to fill that need. These professionals should find out if CCLS are available to

intervene in their practice. If so, they should start referring patients and families to Child Life. If not, they should see what changes can be made to make CCLS available. If it is a case of a limited CCLS staff within the hospital, orthopaedists, orthotists, and physical therapists should communicate their desire for more CCLS to the hospital directors and others who are in charge of hiring CCLS and expanding Child Life programs.

CCLS, too, can use the evidence within this thesis to assert the needs of psychological support in AIS treatment and make a case for their ability to fill the need. This does not mean all CCLS should request to be involved with the treatment of AIS, but those who have a special interest in the AIS population should let their directors and supervisors know. That way, on a trial basis, they can work with patients and families who are dealing with AIS. If the interventions appear to be worthwhile, the hospital can consider hiring more CCLS to maximize the populations, individuals, and families served. In regards to those served, the literature suggests that all patients diagnosed with AIS are at risk of experiencing adverse psychological effects due to the disease and its treatment, but the literature that connected AIS and CCLS only did so in the context of spinal fusion. Those involved with CCLS referral need to recognize this discrepancy and take the psychological health of patients in all stages of treatment seriously and give them equal opportunity to meet with a CCLS.

Patients and families can also let the professionals they encounter during AIS treatment know that they need and want psychological support, specifically from a CCLS. Once they communicate the need, professionals can work with them to fill the need.

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